




Participant User Guide


Register for an Account


- Step 1: Read the Terms and Conditions and Privacy Policy and attest to the statements provided. When you are finished with this page, click “Next”.


Featuring





Registration











Terms & Conditions

Contact Info

Notifications

Review & Submit

Confirmation

Below are links to the IAMRARE Terms of Use and Privacy Guidelines. The purpose of these documents is to outline your rights and responsibilities when using the platform. These documents include: 1) Standard policies for all studies on this platform, 2) A privacy statement that details how your data can be used, 3) Information outlining the unacceptable uses of the platform, and 4) Information about how to address questions and issues.

Acknowledgements:

☐

You are at least 18 years of age, the age of majority in your state, province or country, and able to consent on behalf of yourself and/or an individual that you have legal responsibility for. *

☐

You agree to support the Platform's research activities by providing truthful, appropriate information and to not do anything that will put the Services or the information in the Platform at risk. *

☐

You understand that NORD will use reasonable efforts to keep the information you enter on the Services safe, but no data transmissions over the Internet can be guaranteed to be 100% secure. The information you provide will be available to authorized users at NORD for platform maintenance and research activities, as well as to the sponsor of the studies you consent to participate in. *

☐

You agree to the [Terms and Conditions](#) & [Privacy Policy](#) *

[Return to login](#)

Next

- Step 2: Enter your personal information in the spaces provided. When you are finished with this page, click “Next”.

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ippf International Pemphigus & Pemphigoid Foundation

Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

Country of Residence *

First Name * Last Name *

E-mail *

[Return to login](#) [Previous](#) [Next](#)

- Step 3: Select whether you are interested in being contacted by NORD regarding available studies. When you are finished with this page, click “Next”.

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Registration

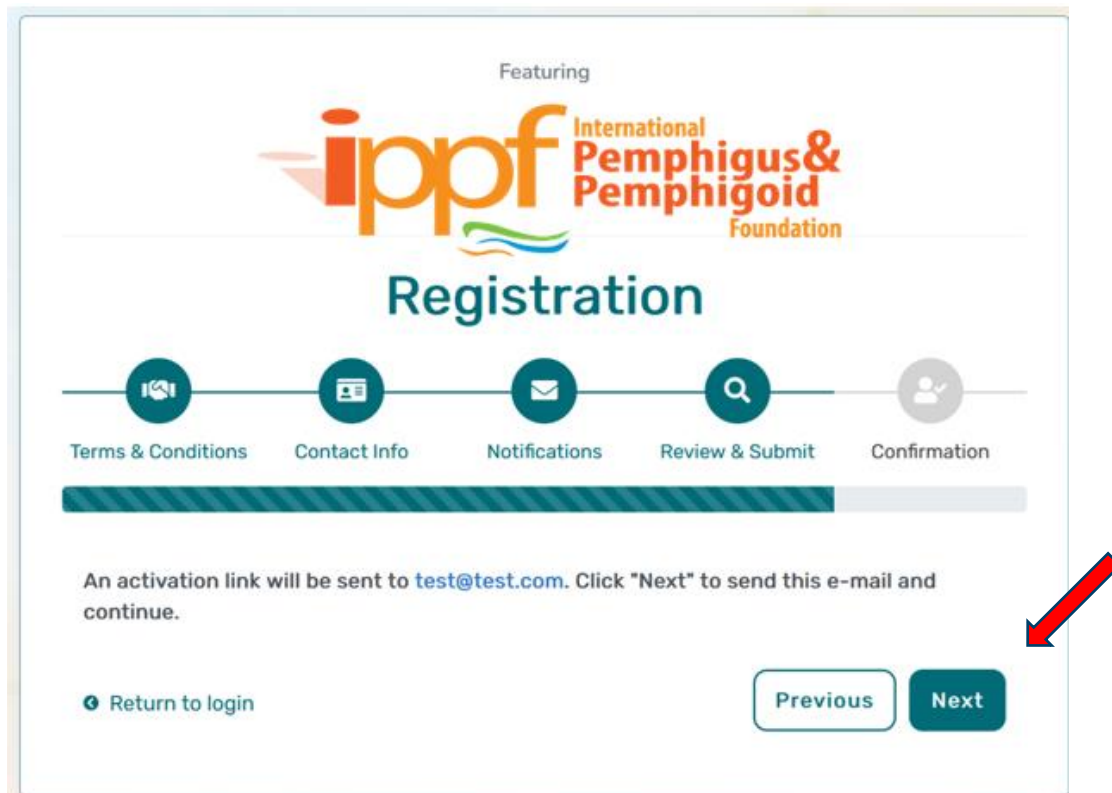
Terms & Conditions Contact Info Notifications Review & Submit Confirmation

I am interested in NORD contacting me regarding available studies. *

☒ Yes ☐ No

[Return to login](#) [Previous](#) [Next](#)

- Step 4: Select “Next” so that an activation link is sent to your e-mail to complete registration.



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Registration

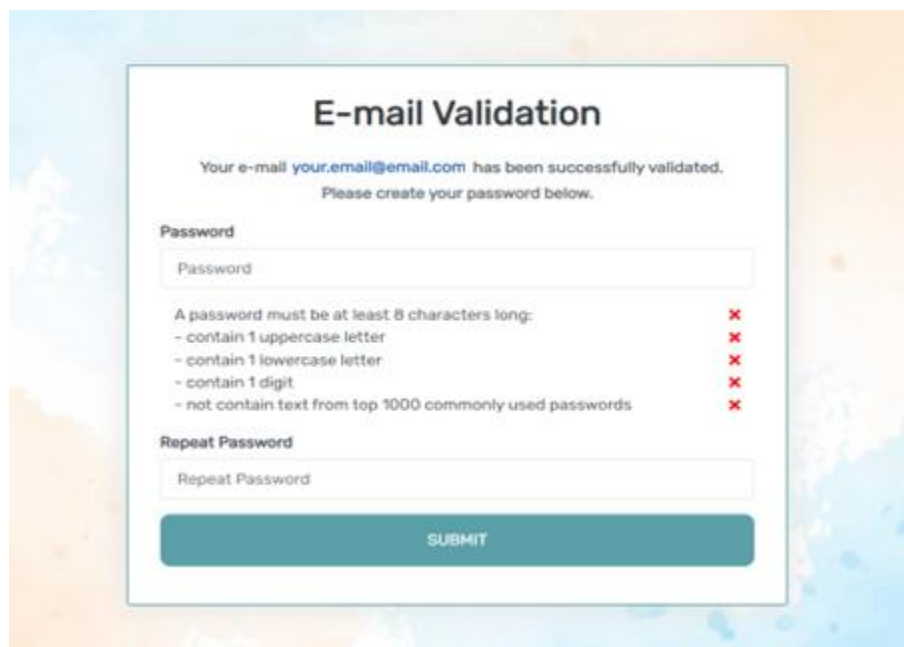
Terms & Conditions Contact Info Notifications Review & Submit Confirmation

An activation link will be sent to test@test.com. Click "Next" to send this e-mail and continue.

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A red arrow points to the "Next" button.

- Step 5: Click the link you are sent via e-mail. Please check your Spam folder if you do not see the e-mail. You will be taken to the following screen in a new tab within your browser. Set your password and click “Submit”.



E-mail Validation

Your e-mail your.email@email.com has been successfully validated.
Please create your password below.

Password

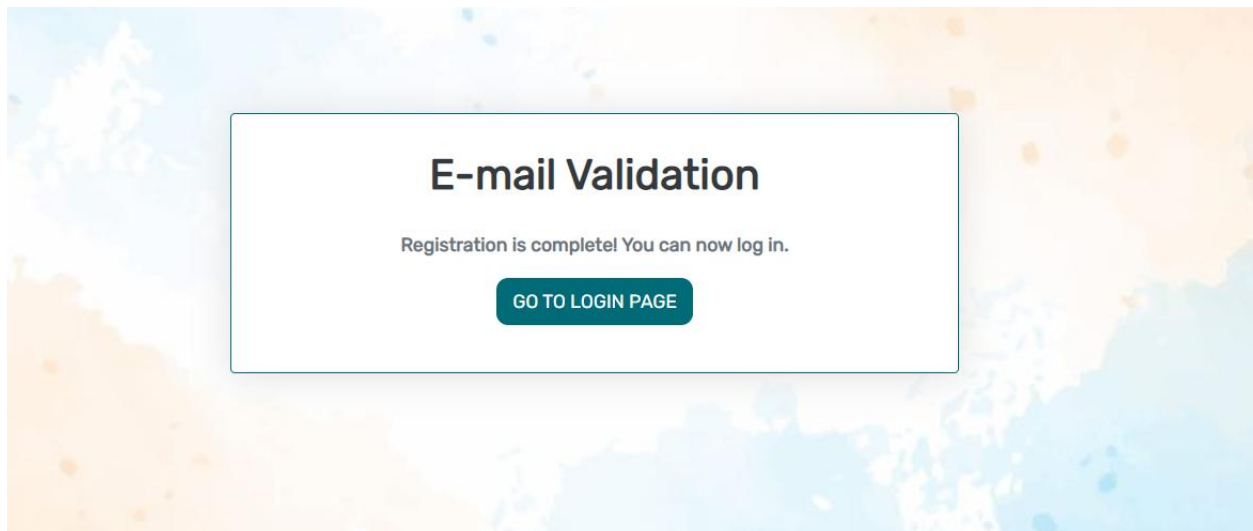
A password must be at least 8 characters long:

- contain 1 uppercase letter
- contain 1 lowercase letter
- contain 1 digit
- not contain text from top 1000 commonly used passwords

Repeat Password


[SUBMIT](#)

- Step 6: Your validation is now complete. Select “Go to Login Page”.



- Step 7: Log in using your new e-mail and password.

IAMRARE®
LOGIN



☐ Keep me logged in

[↪ LOGIN](#)

[⚠ Forgot Password](#)

[+ Create an Account](#)


By logging in, you agree to NORD's [Privacy Policy](#) & [Terms and Conditions](#)



Add a Participant

- Step 1: To start, click Create New Profile.

English ▾

**ippf** International Pemphigus & Pemphigoid Foundation

Welcome, Jane!

Welcome to the IAMRARE[®] program, home of **International Pemphigus & Pemphigoid Foundation Natural History Registry**.

If you are a new user, click on the **Create New Profile** button below.

If you are transferring a record from another IAMRARE account, click on the **Transfer a Record** button below.

Transfer a Record

Create New Profile

Don't show this again

- Step 2: Select who you will be providing information about.

**ippf** International Pemphigus & Pemphigoid Foundation

Add a Participant

Are you adding yourself or another person?

Yourself

Someone else

- Step 3: Fill out the Participant's information.

Add Participant
×

Who Is Being Added as a Participant? ?
☐ Self
☒ Other

Preferred First Name *

Current Last name *

First Name on Birth Certificate *

Middle Name on Birth Certificate *

Last Name on Birth Certificate *

Date of Birth * ?

Sex Recorded on Birth Certificate * ?

Country of Residence * ?

State/Province/Region of Residence * ?

Country of Birth *

City/Municipality of Birth *

What Is Your Relationship to ? * ?

Consent to the Study

- Step 1: Click on “Yes, complete consent for this participant.”


×

Thank you for registering your first participant!

Would you like to consent to participate in International Pemphigus & Pemphigoid Foundation Natural History Registry?

←

- Step 2: Scroll down and read through the consent form thoroughly. Once you finish each page, click the “Next” button. Once you reach the Authorization form, read through the statements thoroughly. If you are comfortable consenting to participate in the study, please read each statement and authorize your consent. After checking the boxes, click “Next.”

Consent to International Pemphigus & Pemphigoid Foundation Natural History Registry

Jane Smith

Consent Overview

Those eligible to participate in our study include:

Participant: An individual diagnosed with Pemphigus and Pemphigoid who is at least 18 years of age, the age of majority in their state, province or country, and able to provide consent for themselves.

Legally Authorized Representative: an individual (such as a family member or guardian) who is legally responsible for the healthcare of the Study Participant who is a minor (child under the age of 18) or an adult who is unable to contribute their own data. This individual must also be at least 18 years of age and the age of majority in their state, province or country.

Designated Representative: A legal adult who was the caretaker of an individual who passed away from Pemphigus and Pemphigoid, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had Pemphigus and Pemphigoid and who had knowledge and participated in their medical care. This individual must also be at least 18 years of age and the age of majority in their state, province or country.

Please tell us about the Participant you would like to enroll in this study. *

☐ They are a minor or an adult who is unable to contribute their own data. I am currently their caregiver.

☐ They were a patient with Pemphigus and Pemphigoid. I participated in their medical care.

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Consent to International Pemphigus & Pemphigoid Foundation Natural History Registry

Jane Smith

Consent for a Person with a Legally Authorized Representative (Caregiver)

Title: IPPF Natural History Registry Study

Principal Investigator: Mirella Bucci, IPPF Natural History Registry Study Principal Investigator

Phone: 916-922-1298

E-mail: registry@pemphigus.org

Sponsor: The International Pemphigus and Pemphigoid Foundation

Key Information

You are invited to take part in a research study for individuals with Pemphigus and Pemphigoid on behalf of the person in your care. We hope that this form will help you decide whether or not to participate, but you can also call or e-mail the study staff at the contacts above if you have any other questions.

Things you should know:

We are doing this research to collect information from participants (or their authorized respondents, heretofore referred to collectively as "participants") who are affected by pemphigus and pemphigoid.

If you choose to participate on behalf of the participant, you will be asked to provide information about your disease experience and be followed throughout the course of your life by contributing data at varying intervals throughout the course of the study. Data will be collected at the start of the study (baseline), at 3- and 6-month time points or can be updated by you as needed. Data will be collected on demographics, quality of life, medical history, disease phenotypes, disease-related events, personal experience with

Previous Next

Jane Smith

Authorization

The following statements are intended to:

- Make sure that you have had the time and opportunity to consider whether you and the Study Participant want to participate in this registry;
- Have had your questions answered; and
- Agree to participate in the study as described.

You will be asked to acknowledge:

- That you have read the consent form and have no further questions about the registry and the Study Participant's participation;
- That you wish to provide the Study Participant's personal data to the registry for the purposes of the Study;
- That you allow for this data to be used for future research;
- That you have explained the study to the Study Participant to the extent they are able to understand; and
- That you are of legal age.

This is a web-based form. Your digital signature is the same as if you had signed your name to a paper document. By answering "Yes" to all of the following statements, you are giving your consent to participate in the IPPF Natural History Registry Study on behalf of the Study Participant. After signing, a copy of the consent form will be e-mailed to you. If you cannot comfortably answer "Yes" to these statements, please do not check the consent boxes in the following section.

- ☐ I have read this Consent and Authorization Form to provide the Study Participant's personal and medical data to be shared for the purpose of research. All my questions about the IPPF Natural History Registry Study have been answered to my satisfaction, and I understand the purpose of the registry and the risks of participation.

[Previous](#)[Next](#)

- Step 3: Once you click "Next" and reach the Thank You page, click "Continue to Opt-Ins".

Consent to International Pemphigus & Pemphigoid Foundation Natural History Registry

X

Jane Smith

Please continue to select your opt-ins. Once you have made your selections, please click Save and Review. You will then be ready to take surveys and participate in this study.

[Previous](#)[Continue to Opt-Ins](#)

- Step 4: Once you click "Continue to Opt-Ins" read through the opt-ins thoroughly. If you would like to receive information about the topic, check the box, and click "Save and Review".

Opt-Ins for International Pemphigus & Pemphigoid Foundation Natural History Registry

X

Select Opt-Ins for this study

- ☐ Interest in hearing about other studies from [International Pemphigus & Pemphigoid Foundation](#)
- ☐ Interest in hearing about relevant clinical trials
- ☐ Interest in donating specimens or DNA (biobanking) for future research
- ☐ Interest in genetic testing
- ☐ Interest in learning more about [International Pemphigus & Pemphigoid Foundation](#)
- ☐ Interest in signing up for [International Pemphigus & Pemphigoid Foundation's](#) newsletter
- ☐ Support from [International Pemphigus & Pemphigoid Foundation](#) Ambassador / Care Coordinator
- ☐ If eligible, I have interest in receiving [International Pemphigus & Pemphigoid Foundation's](#) merchandise that would be sent via electronic or postal mail

[Save and Review](#)

- Step 5: Once you've reviewed your consent, click "Close". You will then have access to start taking surveys.

Taking Surveys

- Step 1: Click on your Participant.

IAMRARE® Home Help Settings Hi, Jane!

Good Morning, Jane!
Member since Mar 27, 2025

Participants
Select a participant to view their studies. Click on the "Add Participant" button above to add a participant.

Participants List:

Participant	Surveys
Jane Smith 5-May-2000 8 pending surveys	8 pending surveys

Shortcuts: Request Transfer, Consent/Opt-Ins

Notifications (0): No new notifications.

- Step 2: Click on the appropriate study.

[Back to participant list](#)

Jane Smith
5-May-2000

Enrolled Studies
Click a study to see the list of surveys. Click the **i** icon to see more information about the study. Click "Search Studies" above to find additional studies.

Search Studies

Study Card: International Pemphigus & Pemphigoid Foundation Natural History Registry
International Pemphigus & Pemphigoid Foundation
Consented
8 pending surveys

Shortcuts: Request Transfer, Consent/Opt-Ins

Notifications (0): No new notifications.

- Step 3: Click "Take Survey" for an available survey.

[Back to study list](#)

Jane Smith
5-May-2000

International Pemphigus & Pemphigoid Foundation Natural History Registry

Surveys: 8 pending

Survey Status: All (8) Complete (0) Pending (8)

Progress: 0% Getting Started Not Started

Take Survey

View Responses and Reports

- Step 1: Once you have submitted a survey, you are able to view your responses to that survey as well as the graphs for any questions that are programmed to show graphs. Click “View Responses” to see your completed survey. Click “Reports” to see any available graphs.

The screenshot shows the user profile for Jane Smith (5-May-2000) at the top. Below is the study title: "International Pemphigus & Pemphigoid Foundation Natural History Registry". A "Surveys" section indicates "6 pending" with a bell icon. A filter bar shows "All (8)", "Complete (2)", and "Pending (6)". Two survey entries are listed:

- Getting Started** (Completed on 27-Mar-2025): Includes "View Responses (1)" and "Reports" buttons. Two red arrows point to these buttons.
- Participant Profile** (Completed on 27-Mar-2025): Includes "View Responses (1)" and "Reports" buttons.

View Consent and Opt-Ins

- Step 1: Once you have consented to the study, you are able to view your consent at any time. Navigate to the Enrolled Studies page. Then, click “Consents/Opt-Ins” to see your consent and opt-ins.

The screenshot shows the "Enrolled Studies" page for Jane Smith. A "Back to participant list" link is at the top left. A "Search Studies" button is at the top right. Below the header, there's a section for "Enrolled Studies" with instructions. To the right, a "Shortcuts" section contains two buttons: "Request Transfer" and "Consent/Opt-Ins". Red arrows point to the "Consent/Opt-Ins" button and the "Search Studies" button.

- Step 2: You may revoke your consent at any time by clicking “Revoke”. You may also edit your Opt-Ins by clicking “Opt-Ins”.

The screenshot shows the "Consents/Opt-Ins" page for Jane Smith. A "Back to study list" link is at the top left. Below the header, there's a table with the following columns: Study Name, Consent Status, Consented On, and Actions.

Study Name	Consent Status	Consented On	Actions
International Pemphigus & Pemphigoid Foundation Natural History Registry	✓ Consented	27-Mar-2025	View Consent Revoke Opt-Ins

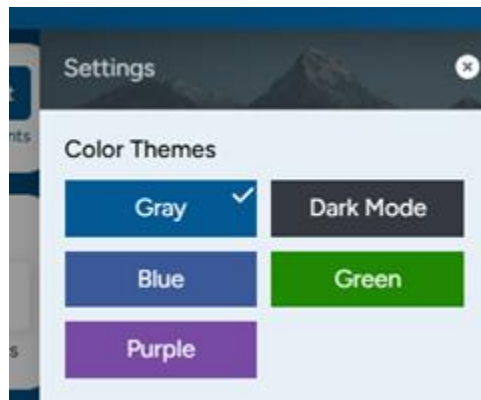
Red arrows point to the "Revoke" and "Opt-Ins" buttons in the Actions column.

Dark Mode Settings

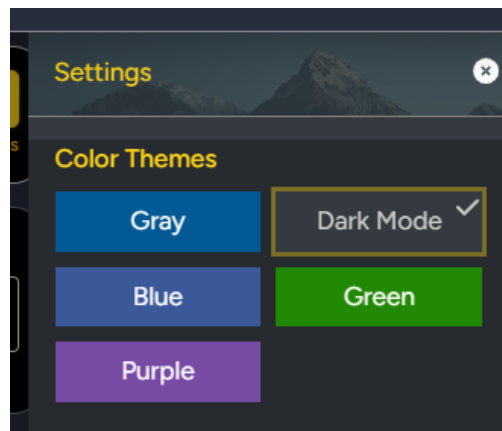
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.



- Step 3: Exit the Settings menu, and your selection will be saved.

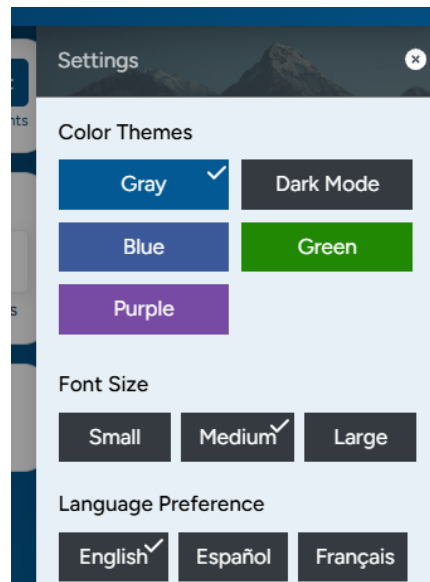


Display Settings

- Step 1: You can change the platform display settings. First, click Settings.



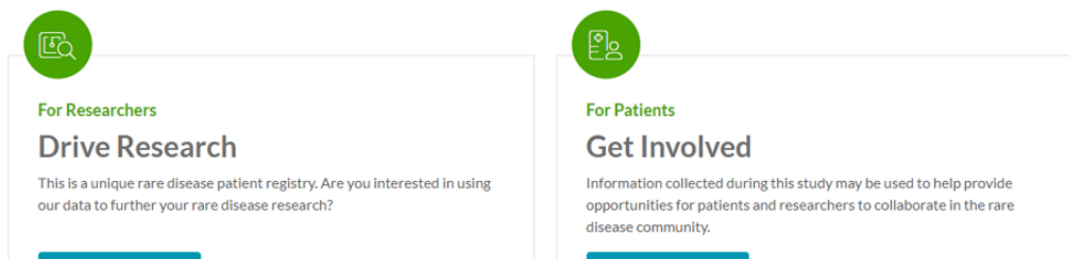
- Step 2: Select a color theme, a font size, or language preference.

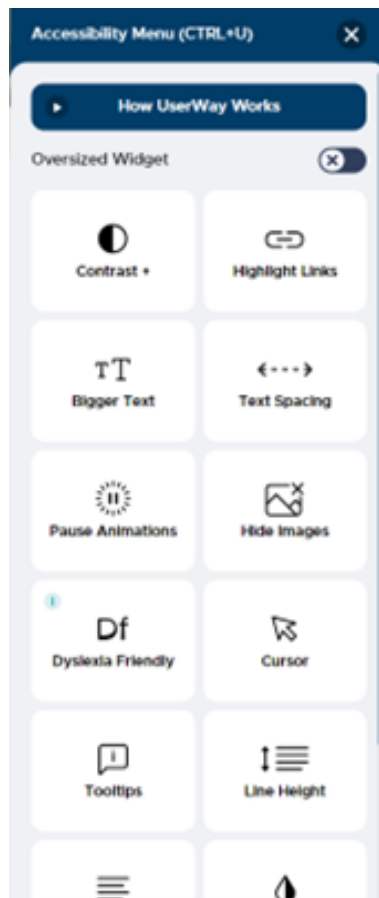


- Step 3: Exit the Settings menu, and your selection will be saved.

Microsite Visibility

- Step 1: You can change how you view the microsite (pemphigus.iamrare.org) using an Accessibility menu. Click the icon of a person at the bottom of the screen. You are able to change the settings such as the contrast, text sizing, and text spacing.





Need Assistance?

- Step 1: If you need help while using the platform, click Help.
- Step 2: Select an Inquiry Type and type a message.

A screenshot of a mobile application's 'Have a question?' form. The form is a vertical list of elements: a blue header with the title and a close button (X), a paragraph of text explaining the purpose of the form, a dropdown menu for 'Inquiry Type' with the placeholder text '-- Select Inquiry Type --', a text input field for 'Message' with the placeholder text 'Your message', and two buttons at the bottom: 'Cancel' and 'Submit'. The form has a light blue background and a blue border.

- Step 3: Click Submit.

- You may also contact the study sponsor directly by using the contact information shown on your dashboard or the study website.

View Responses ①

Reports

View Responses ①

Reports

Take Survey

Take Survey



International
Pemphigus &
Pemphigoid
Foundation

pemphigus.org/

Contact

Marc Yale

Phone

855-473-6744

E-mail

registry@pemphigus.org

IRB E-mail

info@northstarreviewboard.org

Social Media

